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ABSTRACT

This pamphlet alerts school psychologists to the educational implications of Tourette Syndrome (TS) and provides information on: the nature of the disorder and its incidence, diagnostic criteria, etiology, treatment, and considerations in testing and classroom accommodations. TS is characterized as a complex neurobiological disorder with involuntary motor and/or vocal tics and associated behavior difficulties. Psychologists can recognize the symptoms of TS and can guide and support youngsters and their families through the critical steps toward definitive diagnosis. As consultants to the school's instructional program, psychologists should consider: direct effects of tics on specific tasks, such as handwriting; interferences in attention as students attempt to inhibit tics in the classroom; medication effects such as drowsiness; and interpersonal problems resulting from the symptoms, such as vocal tics. Types of accommodations that may be made in the classroom include a buddy system for note-taking, opportunity for oral response to tests, extended time on tests, resource room assistance, tutoring, and special schooling. Psychologists can provide school personnel, students, and their families with accurate information about the nature of TS and new developments. Brief annotations are provided on four videotapes and five publications on TS. (Contains 12 references.) (SW)

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# TOURETTE SYNDROME & THE SCHOOL PSYCHOLOGIST

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by: **Rosa A. Hagin, Ph.D.**

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## Introduction

Psychologists working in the schools have unique opportunities for service to youngsters with Tourette Syndrome (TS), a complex neurobiological disorder with a spectrum of involuntary motor and/or vocal tics and associated behaviors. Education is important for youngsters with Tourette Syndrome; it represents a significant rehabilitation strategy that will enable them to realize their potential despite the socially stigmatizing symptoms of the disorder. This pamphlet is written to alert school psychologists to the educational implications of having TS and to direct them to additional information sources. Increased knowledge can only enhance the quality of school services to students with Tourette Syndrome.

## Nature of the Disorder

For more than one hundred years TS has been recognized as a disorder characterized by involuntary, repetitive, stereotypic movements of muscle groups, uncontrollable vocal sounds, and, in a minority of cases, repetition of inappropriate, obscene words. These movements or tics

usually appear in childhood between the ages of two and sixteen years. Symptoms may include one or more of the following: eye blinking, facial grimacing, head twitching, or shoulder shrugging. Tics wax and wane over time with slow changes, so that an old symptom may disappear with a new one replacing it or being added to existing symptoms. Although previously considered a lifelong condition, remissions or marked improvement have been observed in late adolescence or young adulthood.

While motor and vocal tics are the most obvious TS manifestations, some people with TS regard them as the least disabling aspects of the disorder. Attention deficits and hyperactivity may interfere with learning. Compulsive behaviors, obsessional thinking, irritability, low thresholds for frustration, and impulsivity may disturb interpersonal relationships. However, there is great variation in degree, course, and symptoms, with all individuals manifesting their own unique expressions of the condition. Because of the broad range of clinical manifestations, a confirmed diagnosis may be delayed, and the cause of tics may be mistakenly attributed to psychological, respiratory, or ophthalmological conditions. This delay in diagnosis may lead to inappropriate interventions that not only may not help, but may exacerbate problems in the relationships of the youngsters and their families.

## Incidence

TS has been traditionally regarded as a low-incidence disorder, although more careful epidemiological studies and increased awareness of the symptoms have raised some questions about this view. Cohen, Bruun, and Leckman (1988)

have estimated that Tourette Syndrome may affect one person in 2500 in its fullblown form and perhaps one in several hundred in its milder forms. Epidemiological studies of regional samples have demonstrated gender and age differences in expression of the symptoms. For example, prevalence rates in the state of North Dakota were found to be 9.3 per 10,000 for boys and 1.0 in 10,000 for girls under the age of 18 years. The gender ratio reported was lower in adults with rates of .77 per 10,000 for adult males and .22 per 10,000 for adult females. These figures strongly suggest a reduction of symptoms during late adolescence and adulthood. The rates of the disorder seem not to vary with respect to race or ethnicity.

Validity of estimates depends to a great extent upon the awareness by both the public and professionals. Since there are as yet no clearly identified biological markers, criteria for identification depend on clinical observation. The changing nature of the symptoms also presents problems for researchers, particularly with milder cases. Finally, the similarity of some early symptoms of TS to other conditions such as Transient Tic Disorder or Attention Deficit Hyperactivity Disorder (ADHD) adds to problems in diagnosis. (Zahner, Clubb, Leckman, & Pauls, 1988)

## Diagnostic Criteria

Identification of the symptoms is not an easy matter. Therefore it is important for school psychologists to be familiar with the diagnostic criteria for Tourette Syndrome as outlined in the *Diagnostic and Statistical Manual of Mental Disorders, 3rd Edition Revised* (American Psychiatric Association, 1980):

1. Both multiple motor and one or more vocal tics have been present at some time during the illness, although not necessarily concurrently.

2. The tics occur many times a day (usually in bouts), nearly every day or intermittently throughout a period of more than a year.

3. The anatomic location, number, frequency, complexity, and severity of tics change over time.

4. Onset before age 21.

5. Occurrence not exclusively during psychoactive substance intoxication or known central nervous system disease, such as Huntington's chorea and post-viral encephalitis.

## Etiology

Although clinical research has done much to advance diagnostic and treatment strategies in recent years, the causes of the disorder are unknown. A shift from the early emphasis on psychodynamic factors to "constitutional" factors occurred in 1961 with the successful treatment of patients with haloperidol. Neuroanatomical studies have been inconclusive, but alterations within the basal ganglia, abnormalities in its major pathways, or lesions in other brain regions that interconnect with the basal ganglia are suspected to be involved. (Singer & Walkup, 1991) Investigators believe that biochemical abnormalities at locations within the brain circuits related to motor functions could produce the TS symptoms. Based on the patients' response to medications, dysfunction of central neurotransmitter systems has been suggested as a cause. In the early 1980's major research emphasis was placed on dopaminergic systems and hyper-sensitivity of dopamine receptors.

Recent studies have shown the etiology to be more complex.

Evidence from studies of family groups and twins has highlighted complex genetic factors and gender differences in expression of the symptoms. These studies have also documented a substantial relationship between TS and other conditions such as obsessive-compulsive disorder and chronic tics. Pauls and Leckman (1986) have proposed a genetic model of transmission of vulnerability through a single major autosomal gene. However, genetic vulnerability accounts for only a portion of the expression of the disorder. The final expression may be a function of gender-specific neuroendocrine factors such as the effect of androgens on the developing brain, the presence of other conditions such as ADHD, pre- or postnatal environmental stress severe enough to activate neurochemical systems, or exposure to pharmacological agents. (Leckman, Riddle, & Cohen, 1988)

## Treatment

Because research has shown TS to be a multiply determined disorder in which genetic vulnerability, environmental stressors, and emotional factors combine to produce neurophysiological changes, treatment must also be broad in scope. Management of the youngster with TS involves more than control of tics and vocalizations; it involves the understanding of all sources of stress, whether they come from the family, the school, peers, or having the disorder itself.

This understanding has its foundations in comprehensive, multidisciplinary diagnosis. A comprehensive plan of intervention involves educational,

psychotherapeutic, behavioral, familial and medical components, although all services are not necessarily needed on a continuing basis. However, with so many disciplines involved, treatment can become fragmented and confusing to the family. Therefore, the designation of a central figure, someone who is available to the family as problems arise and who can take responsibility for ensuring that the services needed at a particular time are provided, is essential. (Silver & Hagin, 1990)

Although medication may reduce the motor and phonic tics, it does not cure the disorder. However, when symptoms are particularly disturbing to the youngster and when they impair social and educational and/or vocational functioning, the physician has a number of medications to call upon: haloperidol (Haldol), pimozide (Orap), fluphenazine (Prolixin), clonidine (Catapres), as well as several other pharmacotherapeutic agents currently under consideration. However, no drug is entirely free of side effects – short term effects (cognitive blunting, lethargy, depression, weight gain), long term toxicity, the meaning of taking medication to the youngster and his family – all these factors must be taken into account in effective treatment planning.

Behavioral interventions have also been used with tics and vocalizations. Behavior approaches including massed negative practice, contingency management, relaxation training, self monitoring, and habit reversal have had some success with some patients, although none has been universally successful. Azrin & Peterson (1988) recommend a multicomponent program using several of these approaches with specific training in generalization which they have found useful with nonresponders to medication.

Alternative therapies, primarily in the nature of allergy control and nutritional supplements, have been reported. In this connection, Bruun (1984) has pointed out that scientific validation of any treatment requires improvement in symptoms significantly higher than the 25% of changes inherent in the waxing and waning of symptoms that occur spontaneously. Controlled studies have demonstrated a significantly high rate of improvement with drugs such as haloperidol, pimozide, and clonidine, but no such results have been documented for most alternative therapies.

## Clinical Contributions of School Psychologists

As clinicians, school psychologists can contribute substantially to the management of youngsters with TS from the very beginning of the diagnostic process. Like most people, these youngsters may approach psychological testing with some degree of anxiety. They may handle this anxiety very differently from other youngsters referred for psychological services. One common occurrence is the inhibition of symptoms. It is not unusual for youngsters with TS to control tics for short periods of time. This cannot continue indefinitely, for eventually tension mounts and finds motor or vocal expression. Such inhibition of symptoms could be confusing to psychologists who base their assessments of a youngster's learning problems on a limited sample of behavior. Limited observation could result in the belief that the problem was really a figment of the imagination of a neurotic parent. Such a conclusion might result in a recommendation that special educational services were unnecessary, when indeed they were badly needed.

Effective diagnostic service requires the psychologist to allocate adequate time for evaluation and to arrange to see the youngster in a variety of settings. By providing for the variations in behavior and attention that accompany the disorder, psychologists can help to ensure valid assessment of these youngsters' strengths and needs.

In addition to the cognitive implications of Tourette Syndrome, there can be behaviorial problems associated with the condition. These can be understood when taken within context of the youngsters' reactions to confusing symptoms that result in loss of control of actions (and sometimes thoughts) that are socially disabling. The disorder is unpredictable, with periods of apparent remission of symptoms followed by explosions of the tics. Frankel (1983) has commented that this unpredictability is, in itself, a source of stress.

A variety of defensive systems may be called into play. Social withdrawal, denial, depression, dependency, anger, and rage may be common reactions to the pain and frustration of trying to cope with the disorder. Often it is in the home where the full force of these reactions is felt. Skilled clinicians who understand the relationship of TS to these reactions can provide empathic support to the youngsters and their families. For a more detailed discussion of associated behavior problems, the psychologist should read *Tourette Syndrome and Behavior.* (Bruun & Rickler, 1991) This helpful resource can be obtained from the Tourette Syndrome Association, Inc.

Diagnostic services should focus on the whole person, not just the problems. This means assessing the youngster's strengths as well as the effects of the disorder.

## School Psychologists as Educational Consultants

As educational consultants school psychologists can do much to ensure that students with TS enjoy the full benefits of their educational programs. These students may experience learning problems at a number of different levels. There may be primary problems implicit in the disorder itself, as well as secondary effects as the individual attempts to deal with the impact of the disorder on total functioning. Several factors to consider are:

- Direct effects of the tics upon specific tasks (e.g. performing the skilled perceptual and motor actions required in handwriting);
- Interferences in attention as the student attempts to inhibit the tics in the classroom;
- Medication effects, such as the drowsiness or blunting of cognitive processes associated with the use of some medications prescribed to relieve symptoms;
- Interpersonal problems resulting from the symptoms (e.g. vocal tics may be perceived as violations of school behavior standards; motor tics may cause rejection by peers, social isolation, teasing or scapegoating).

## Testing Considerations

Because of the attentional problems that frequently accompany TS, timed educational test results may underestimate the student's skills. This is particularly true when the task requires extended independent work (i.e. conventional achievement tests). A valid assessment should utilize a variety of achievement measures, such as curriculum-based assessment or such individual

achievement tests as "Key Math," the "Woodcock-Johnson Tests of Achievement-Revised," the "Wechsler Individual Achievement Test." Those individual formats help to neutralize the effects of attentional problems because they are cued by the examiner and present only a few items at a time. These individual measures are also useful for comparison with the results of more conventional achievement batteries given as part of the school's general testing program.

Modifications in the administration of any formal achievement test battery are necessary. School achievement is an area in which students with TS may excel. Their troubles in demonstrating what they know on tests should not keep them from receiving the most challenging educational experiences they can handle.

## Classroom Provisions

Most youngsters with TS learn best in a moderately structured classroom, although there are individual variations. They need the guidance of clearly articulated directions from teachers, but they also need some opportunity for freely expressed physical activity. Sometimes, if tics are in the waxing stage, students may need a place of refuge such as a brief time in the school nurse's office, a corner of the library, a counselor's office, or any other private area where the expression of a symptom would not be embarrassing.

As with any school age sample, some youngsters will have specific learning disabilities. Others may have more generalized learning disorders due to the nature of TS itself and the behaviors associated with it. A broad based assessment of both strengths and needs should determine the provi-

sions necessary to ensure appropriate educational progress. The range of accommodations might include:

- A buddy system for note-taking
- Opportunity for oral response to tests
- Extended time on examinations
- Use of a tape recorder in lecture courses
- Resource room assistance
- Tutoring
- Special schooling

## Mental Health Considerations

As mental health professionals consulting in the schools, psychologists have the opportunity to influence the attitudes of the significant people in the lives of youngsters with TS. The attitudes of peers, teachers, and parents have a profound influence on a successful adjustment to the disorder. These youngsters may feel isolated from people their own age. Sometimes this feeling stems from the youngster's own poor self esteem, but other times, the feelings are indeed a realistic perception of the group processes occurring in the school. Thus, while it is necessary to counsel the youngsters to help them build positive feelings about themselves, it is equally important to work with their peers and teachers to ensure acceptance within the school community.

Needless to say, this process should be accomplished with tact. Acceptance should not be based upon a patronizing emphasis on the disability, but upon honest acceptance of the individual as a person. Sometimes the bizarre symptoms of TS make these relationships difficult. As mental

health consultants, psychologists can help to modify this situation by becoming positive role models for the children in the school.

Psychologists can serve as sources of information about mental health concerns for teachers and other members of the school staff. In this role, they can work with teachers, not only by supplying information about the nature of TS and the present status of the youngster's treatment, but also by helping to build positive attitudes among the school staff. These school personnel can, in turn, act as appropriate role models for the students in their relationships, not only with regard to the youngster with TS, but for all people with handicapping conditions.

Important resources for encouraging attitude change are the films and videos that are available through the TSA National Office. For example, the video "I'm a Person Too" features two children and three adults from diverse backgrounds discussing their experiences living with this disorder. This video is a good starting point for an orientation discussion with older students. Another film, "Stop it! I Can't," can serve the same purpose with middle grade children who may be the classmates of a child with TS. Professional films are available from TSA for inservice training of staff members.

School psychologists will have many contacts with the families of youngsters with TS. These relationships can be mutually helpful. Not only can the psychologist provide understanding and support when the complexities of the disorder affect the family, but parents can also be a source of information invaluable to the busy psychologist who does not always have the opportunity to keep abreast of current information on this developmental disability.

## Scientific Considerations

As scientists, psychologists have the responsibility for basing their conclusions, interpretations, and recommendations on data. They will recognize and avoid shopworn cliches that blame parents for any and all problems that children encounter at school. As scientists, they will remain open to new ideas and avoid untried "cures" until those remedies have withstood the test of scientific scrutiny.

As scientists, psychologists also should serve as interpreters of research. TSA's publications are excellent sources of information about developments in the understanding and treatment of this complex disorder. As well-informed professionals, psychologists can help disseminate to the people they serve the growing data-base of information on Tourette Syndrome and its associated conditions.

## Summary

School psychologists can play a significant role in the education of youngsters with Tourette Syndrome:

- As **clinicians**, psychologists can play a key role in recognizing the symptoms and in guiding and supporting youngsters and their families through the critical steps that lead toward definitive diagnosis;

- As **consultants** to the school's instructional program, they can help to ensure youngsters with Tourette Syndrome the benefits of an appropriate education;

- As **mental health professionals,** they can work to build positive attitudes toward people with developmental disabilities, including Tourette Syndrome;

- As **scientists,** they can provide school personnel, students and their families with accurate information about the nature of Tourette Syndrome and new developments in the management of the disorder.

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## ADDITIONAL RESOURCES

### VHS FILMS

**Stop It! I Can't** — For elementary school ages. Written to create sensitivity and reduce ridicule among their peers.

**I'm A Person Too** — Prize winning documentary featuring five people from diverse backgrounds talking about living with TS; depicts the broad range of symptoms.

**Tourette Syndrome: The Parent's Perspective — Diplomacy in Action** — Features E. Collins, Ph.D. and R. Fisher, M.Ed., providing guidance to TS families on school advocacy issues.

**An Inservice Film For Educators** — A new aid for teachers to help understand the complexities of teaching children with TS. Includes explanation of the complexities of TS and suggests interventions that work. Available January, 1994.

### LITERATURE

**Coping with TS — A Parent's Viewpoint** — E. Shimberg. Covers parental and family acceptance, behavior management. (Revised 1993)

**TS & the School Nurse** — S. Ort, R.N. Comprehensive guide to educational, social and medical implications.

**Problem Behaviors & TS** — Drs. R. Bruun, and K. Rickler. Describes recent research and what is now known about the relationship of a variety of behaviors and TS. Contains helpful advice by Emily Kelman-Bravo, CSW, MS about the management of problem behaviors for families and individuals with TS. (Revised 1993)

**Discipline and the Child with TS: A Guide for Parents and Teachers** — R. Fisher-Collins, M.Ed., 1993. Helps children redirect impulses and compulsions through teaching cause and effect relationships. Included are techniques and disciplining children without the use of aggression or intimidation.

**An Educator's Guide to Tourette Syndrome** — S. Bronheim, Ph.D. Covers symptoms, techniques for classroom management, attentional, writing and language problems.

**An up to date Catalog of Publications and Films, including prices, can be obtained by writing to:**

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